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Planning for End-of-Life Health Care Decisions

What National Survey Results Reveal

By Linda S. Whitton

One of the most publicized legal controversies in 2005 was the protracted dispute in Florida between the husband and parents of Terri Schiavo over discontinuation of her artificial nutrition and hydration. The resulting public debate about this very private matter raised once again the importance of advance planning for end-of-life health care decisions. But long before the Schiavo dispute reached the public domain, the Section of Real Property, Probate and Trust Law was actively engaged in public education about health care advance directives.

National Health Care Decisions Week

In 2000, with grant support from the Health Resources and Services Administration of the U.S. Department of Health and Human Services, the Section launched a five-year annual campaign known as National Health Care Decisions Week. Co-sponsors included the American Medical Association, the National Bar Association, the National Medical Association, and numerous ABA sections. During the campaign, state and local bar associations sponsored community programs on advance directives and organ and tissue donation, and volunteer lawyers assisted attendees with the preparation of living wills, health care powers, and donation declarations.

Before this campaign, advance directives literature speculated that only 15% to 20% of Americans had any form of advance directives. This low percentage as well as the significant need for organ and tissue donors prompted creation of National Health Care Decisions Week. The campaign was designed on the premise that access to information about advance directives and organ and tissue donation combined with assis-

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tance in completing directive and donation documentation would significantly increase the percentages of people who choose to engage in advance planning for end-of-life health care decisions.

To evaluate the effectiveness of the campaign, the Section prepared a survey that program sponsors were encouraged, but not required, to distribute to attendees. Survey questions were designed primarily to assess what percentage of attendees had engaged in end-of-life health care planning before the community programs and what effect education had on attitudes about advance directives and organ and tissue donation.

Program Sponsorship and Attendance Data

Sponsoring bar associations were encouraged to report program attendance data to the Section, but a number of participating bar associations did not return response forms because they were not seeking grant reimbursement for their expenses. As a consequence, the participation data reported to the Section is actually an understatement of total campaign participation.

Based on reported data over the five-year campaign, a total of 248 programs were sponsored by 90 different bar associations for 13,898 attendees. Programs were held in 27 states, the District of Columbia, and the Virgin Islands. Table 1 provides for each year the total number of participating bar associations, states, programs, attorneys, donated attorney hours, and attendees.

Survey Data

The optional participant survey posed a series of questions about health care advance directives and organ and tissue donation. Questions about advance directives were segregated from questions about organ and tissue donation to keep the responses properly referenced. Program attendees were asked whether, before attending the community program, they had health care advance directives or had expressed an intention to

become an organ and tissue donor. If the answer to either question was no, the respondents were asked to indicate whether they were planning to complete health care advance directives or to become an organ and tissue donor as a result of attending the program. Respondents were also asked whether they learned new information about advance directives or organ and tissue donation and whether the program changed their views. The total number of respondents for the five-year campaign was 1,373. Table 2 on page 40 summarizes by year the percentage responses to individual questions.

The aggregate averages of the responses over the five-year campaign provide insight into public attitudes about advance directives and organ and tissue donation and the role public education may play in increasing advance planning for end-of-life health care decisions. Although a majority of respondents indicated that they did not have advance directives before attending the program (62%), approximately half of that group decided to appoint a medical agent (51%) and to execute a living will (49%) as a result of attending the program. It may be that those who chose to attend the programs were predisposed to engage in advance planning, but the effectiveness of pub-

lic education was also substantiated by responses to other survey questions. An average of 82% indicated that they learned new information about advance directives and 59% responded that they changed their views about advance directives as a result of the program.

Although the sample of survey respondents was not random and therefore may not be representative of the general population (all respondents were individuals who chose to attend a National Health Care Decisions Week program), the response by approximately 40% that they already had some type of advance directive suggests that a higher percentage of Americans may now have advance directives than earlier surmised in the 1990s. But the same data also suggests that a majority of Americans are still without advance directives. It is noteworthy that most of the survey data was collected before the Schiavo controversy and thus can be interpreted free of the media influence generated by that debate.

For organ and tissue donation, 45% of the respondents reported that they had declared an intention to donate before the meeting. Of the remaining 55%, only 24% indicated that they would become organ and tissue donors as a result of attending the

Table 1—Program Participation Data

	2000	2001	2002	2003	2004
Bar Associations	30	12	25	33	25
States	19	10	17	23	15
Programs	71	37	45	53	42
Attorneys	261	97	142	120	128
Donated Hours	1,271	412	1,191	496	494
Attendees	4,548	1,187	1,073	3,494	3,596

program. Thus, the conversion rate of those who decided to become donors was approximately half of that for those who decided to execute advance directives. Notwithstanding the lower conversion rate for organ and tissue donation, the educational value of the program was still substantial with an average of 60% indicating that they learned new information about donation and 35% indicating that they changed their views about donation as a result of the program. These percentages suggest that views about organ and tissue donation may be more resistant to change than those about planning for end-of-life health care with advance directives.

General Conclusions

The five-year survey results from the National Health Care Decisions Week campaign support the conclusion that a combination of public education and access to planning documents is a highly effective means for increasing participation in advance planning for end-of-life health care decisions as well as for increasing the numbers of those willing to donate organs and tissue. The average cost in donated attorney time to educate the nearly 14,000 persons who attended National Health Care Decisions Week programs was approximately 17 minutes per person. Although the true value of these efforts is difficult to quantify for the attorneys and attendees, anecdotal reports indicate a high level of public appreciation for the efforts of the bar associations and attorneys in their communities. Of course, public education and access to documents are only part of the answer to the difficulties posed by end-of-life health care decisions. As was poignantly demonstrated by the Terri Schiavo dispute, it is essential for individuals to discuss their values and preferences with the family members and friends who may be called on to facilitate decision making on their behalf. It is hoped that increased public education and access to the planning documents will be a place for that conversation to begin. ■

Table 2—Summary of Survey Results
(Number of respondents indicated in parentheses)

Responses	2000 (417)	2001 (257)	2002 (170)	2003 (331)	2004 (198)	Aggregate (1,373)
% without advance directives prior to program	73	60	55	54	68	62
% who planned to appoint medical agent	77	64	30	40	44	51
% who planned to execute a living will	63	80	24	41	36	49
% who learned new info about advance directives	88	86	69	78	87	82
% who changed views as a result of program	59	59	54	56	66	59
% who had no organ & tissue donation declaration	58	61	71	45	42	55
% who decided to become donors	47	37	13	12	11	24
% who learned new info about donation	70	65	47	56	63	60
% who changed views about donation	43	41	25	28	38	35